NHIVNA Best Practice

Finding and managing patients living with HIV lost to care: a guide for nurses

Pauline Jelliman MSc, BA, RGN
Former Clinical Lead HIV and TB Community Services, Liverpool, UK

Background

The issue of people living with HIV no longer engaging with their HIV team can be termed 'lost to follow up' (LTFU), 'lost to care' (LTC) or 'need to find' (NTF). For the purpose of this guideline the term LTC will be used and people living with HIV are referred to as patients.

The importance of lifelong retention in care for patients is well understood and documented [1]. First, the individual impact. Engagement in care optimises living well with HIV by timely initiation and maintenance of antiretroviral therapy (ART) and facilitating access to other health and social care services. As patients age with HIV, more complex medical and psychosocial issues can emerge underpinning the cruciality of retention in care ensuring met need. LTC can result in advanced HIV leading to poor physical and mental health, disability or death. Second, the public health impact. Retention in care should result in long-term viral load suppression, preventing onward transmission during condomless sex [2].

HIV nurses working in all settings maintain a pivotal role in identifying and managing those who do not attend (DNA) clinic or disengage completely. It is therefore crucial that we adopt different interventions to maximise contact by tailoring the services we provide. This guidance should be used in conjunction with the previous NHIVNA Best Practice documents [3,4,5].

Keywords

HIV, lost to care (LTC), need to find (NTF), disengagement, retention

Aim

The aim of this document is to guide nurses to:

- review evidence relating to LTC;
- suggest strategies to find and re-engage patients and manage LTC; and
- consider and learn from existing models/experiences/guidance/position statements

Evidence

UK position

In the UK, most patients (97%), have remained in care, with 3025 patients not in receipt of HIV care since 2015. There was no difference in retention by geographical area. LTC was higher in people who inject drugs (PWID) and those born in the Americas, Oceania and the Caribbean compared to those born in the UK. Other groups with higher rates of LTC were those aged 15–24 years, and trans people, although the numbers are small [6]. Some LTC can be attributed to emigration [7]. This highlights the importance of analysing and understanding your cohort of patients in terms of risk of LTC.

Research

Most of the associated research tends to focus on retention in care in the context of its importance, monitoring and reporting. Although retention and LTC are inextricably linked, the evidence base relating to LTC and how to best manage those patients is more limited. LTC is however acknowledged by national and international HIV organisations such as the British HIV Association (BHIVA) and UNAIDS. There are also several local UK publications that tend to explore LTC from a geographical or clinic perspective [8,9], which involves a deep dive into their cohort of patients. Although demographic variables are present across the UK, there are similarities in the reasons why some patients are LTC identified and discussed [3,5,5,10]. LTC can occur at various stages of the HIV care continuum [11,12], such as failure to link with care at diagnosis by either the patient or HIV team. A recent UK study demonstrated that most individuals who were LTC did so within 2 years of entry to care [12]. This suggests improvements in engagement are needed at the point of diagnosis. Moreover, the patients' experience at the point of diagnosis is crucial as negative experiences can impact ongoing retention throughout the care continuum [13].

Retention in care

Retention in care is discussed in BHIVA Care Standards [14]. They recommend service mechanisms that identify

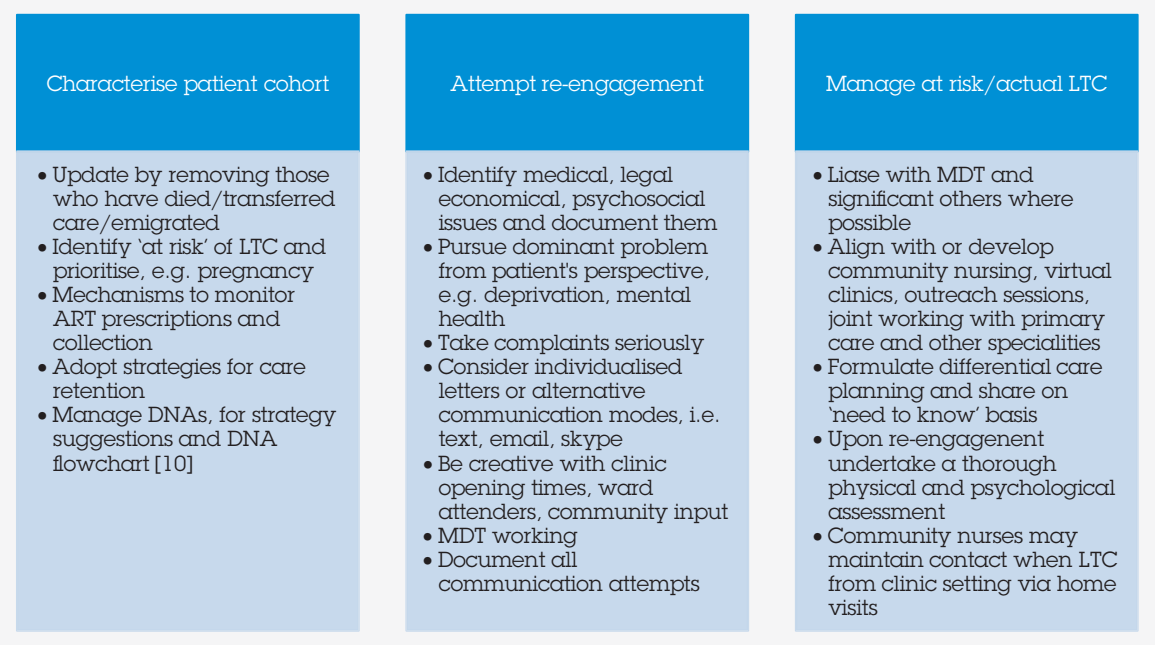

Figure 1: Managing at risk/actual loss to care (LTC). DNA: did not attend; MDT: multidisciplinary team.

and follow up those who are deemed hard to find, but also to explore reasons why the person has disengaged from care, missed appointments or consistently had ART supply issues. BHIVA recommend peer and psychological support should be facilitated when needed, particularly in challenging times such as diagnosis, pregnancy, illness, or during ART starts or switches. Additionally, in the case of patient dissatisfaction, help should be given in changing treatment centres and exploring reasons for concerns or complaint. HIV nurses are pivotal in facilitating BHIVA's recommendations, in collaboration with the multidisciplinary team (MDT) as they tend to know the patient well and engage in promoting partnership working and facilitating tailored care. HIV nurses are therefore well placed to identify risk factors for LTC and lead on strategy development to increase engagement preventing LTC.

Organisations' recommendations

BHIVA have published a good practice position statement regarding prevention and management of loss to follow up in HIV outpatient services that provides excellent guidance on managing DNAs [10], which could be adapted to local need.

European AIDS Clinical Society (EACS) recommend a multidisciplinary approach to HIV testing and ongoing management, however, make little reference to retention and finding those who disengage from care in their 2018 guidelines [15]. They do however recommend regular psychosocial assessments to perhaps alert the HIV team to potential issues that may impact future engagement.

In terms of practical ways of managing those LTC, differentiated care planning may be useful. Described by UNAIDS [16], this recommends compiling different care packages to patients based on their needs, type and frequency of services, and location and provider of services. This underpins the importance of person-centred, individualised care [14]. UNAIDS state:

> *'Meeting the multiple needs of people living with HIV is essential to link and retain people in care'* [16]

Guidance

By considering the guidance in Figure 1 with consideration to the care continuum, interventions can be initiated to pre-empt and so prevent LTC. It could be argued that the input required is labour intensive, however successful re-engagement will bring long-term financial gain to health services. This should not, however, detract from the benefits to the patient and their sexual partner, progressing towards the fourth '90' [17], good health-related quality of life, expanding the care continuum beyond an endpoint of viral suppression.

Closing words

Assessing risk and managing LTC can be challenging for HIV nurses requiring qualities such as: resilience, patience, persistence, collaboration, innovation, flexibility, trustworthiness, enhanced communication, knowledge and approachability.

Within your area of work, it may be useful to explore the role of a retention, or linkage to care worker, to focus on this relatively small but hard-to-reach group of patients. We must accept that some patients may never re-engage despite concerted efforts and will ultimately present at hospital in a seriously ill condition. This may be the result of intentional or non-intentional LTC.

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Conflicts of interest

The author declares no conflicts of interests.

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Correspondence: Pauline Jelliman
pjelliman@blueyonder.co.uk

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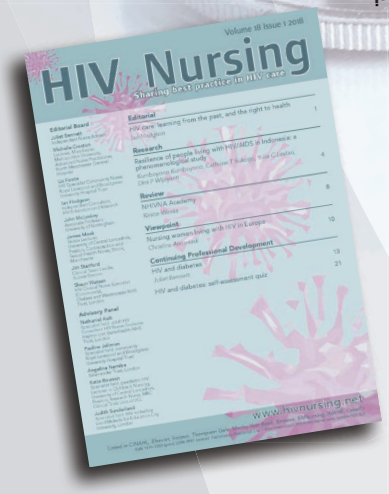

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Email: nhivna@nhivna.org
info@hivnursing.net

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